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Quality of Cancer Registry Data

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Quality of Cancer

Registry Data

by

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Thesis

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Abstract

Cancer registry is a growing field and with data being collected year round the data needs to be of good quality standing. Quality of cancer care is measurable per standards when met within the time frame allotted per care regimen. Cancer programs are evaluating and implementing new process to make their data valid and complete through information technology and connection among hospital-based and community-based practices. The aim of this study is to review the available validity, barriers and utilization related to quality of cancer care data. The studies were consistent among each other in that a concurrent review of data, real-time collection, will be valid to the standards in cancer care. Rapid Quality Reporting System is still in its prime stage and the studies have concluded that using the reporting tool is best.

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Key Terms

- ACOS – American College of Surgeons
- NCI – National Cancer Institute
- CTR – Certified Tumor Registrar
- FCDS – Florida Cancer Data System
- CoC – Commission on Cancer
- NCDB – National Cancer Database
- RQRS – Rapid Quality Reporting System
- CDC – The Center for Disease Control and Prevention
- ICD-O – International Classification of Diseases for Oncology
- CP³R – Cancer Program Practice Profile Report
- NQF – National Quality Forum
- NCCN – National Comprehensive Cancer Network
- SEER – Surveillance Epidemiology and End Results

Quality of Cancer Registry Data

Chapter 1

Introduction

Improving the quality of care requires useful measures of quality, the availability of data, defined mechanism to utilize the data and commitment of providers and institutions. The quality of the care provided is ranked or scored from national standards, indicators and policies that each health professionals follows in their normal day of work.

The definition of quality described by Institute of Medicine as, “The degree to which health services for individuals and populations increase the likelihood for desired health outcomes and are consistent with current professional knowledge” (Hughes, 2008).

A growing area of health services to all patients is cancer care; more and more Americans are being diagnosed with rare or current cancer incidences from infants to the geriatrics. This paper seeks to examine the impact of cancer data and show the point of views of those hospital registries involvements with reporting to NCDB evidence base reporting system within regions of Florida.

Background

Cancer centers are the forefront of National Cancer Institute (NCI) with support from universities and cancer research centers across the United States by developing and translating scientific knowledge from promising laboratory discoveries into new treatments for cancer patients (National Institutes of Health, 2013). Cancer centers are given the title as the institutions that are dedicated to the development of more effective prevention, diagnosis and treatment of cancer approaches. These organizations are run by physicians, nurses, administrative staff, shareholders and other ancillary professional but as the care is being rendered the data is being collected on each cancer incidence and in returned is being reported back to public as an awareness and community outreach.

A cancer registry is one that has matured to be the key source of patterns and quality of care, care tracking and coordination and comparative effectiveness. Each state maintains a cancer registry, supported by the Center for Disease Control’s National Program of Cancer Registries. The National Cancer Institute’s Surveillance Epidemiology and End Results (SEER) programs ascertains more detailed information on patients with cancer within selected regions of the country. In reporting cases to the state registries and SEER it is mandated legislatively that in each report it includes all residents diagnosed with cancer in the state or SEER region. As reporting of cancer cases were conducted, within the abstract there was limited information about the treatment that gave limited value to study the quality of cancer care (Edge et al, 2013).

A national system that is used among more hospital registry data is that of a cancer programs accredited by Commission on Cancer (CoC) of the American College Surgeons. Stephen Edge (2013) reported that there are 70% of patients being seen in hospitals for cancer treatment in which more data is being collected. CoC programs

have standards that they must meet in the quality of care for those initial treatments started at that facility. Each cancer program will report their cases on an annually basis to a single registry called the National Cancer Data Base (NCDB). NCDB ascertains at least 1 million new cases in addition to those follow up cases from each hospital registry. The comparison to the population registry SEER is that hospital registry systems present more granular treatment and continues follow up information annually.

In the past three years CoC has developed a new quality measure mechanism with NCDB reporting called The Rapid Quality Reporting Systems (RQRS). CoC cancer program standard 5.2, for RQRS, its primary objective is to promote evidence-based cancer care as the key to improve the quality of care and patient outcomes (Commission on Cancer, 2011). To date, reporting by hospital registries are being conducted retrospectively and incorporating participation the RQRS it will showcase each registry data concurrently (Commission on Cancer, 2011).

Purpose of Study

In purpose of this study is to review other research evaluating the quality of cancer registry data. The systematic review is aim to not find the conclusion to better quality cancer care but is to educate others on process that has been proven to increase validity and reliability of data.

Significance of Study

Being a cancer database analyst I have taken this area to be more important to my studies of the field and strive to educate others within my field and those not in the field of health information management. Each healthcare facility that houses a cancer surveillance program follows the standards per ACOS but within the organization the team develops how they will capture the data that can be quantified as compliant.

As the history of health information is changing from filing medical records, analyzing by hand to electronic storage and dissemination information cancer registries have stayed up to date in transitioning from record cards to cancer database software. By having viable software that can upload cases to be analyzed the linkage between ICD-9 malignant cancer codes and SNOMED pathological cases CTR abstracting time can be cut in half.

Research Questions

This systematic review is not to prove but educate other registers to different process that have been an asset to increase ones treatment data valid and reliable. Cancer program registries collect treatment data and follow up data day to day and as standards for hospital-based programs there must be data collected and reported in a specific time frame. The CP³R was initiated in 2005 by the National Cancer Data Base and Commission on Cancer to supply a reporting web-based tool in collecting treatment retrospectively against standards to be measured. There was a time lagging gap that hindered treatment data to be valid, reliable and complete after 14 to 15 months ascertained; in 2009 The Rapid Quality Reporting System was initiated to be a faster

reporting tool concurrently. As this began hospital-based programs data was actively keeping up with standard quality measures.

The research question to be answered is: "How is the quality of cancer treatment data is being utilized for valid, reliable and complete reporting?"

Chapter 2

Review of Literature

Findings (see Table 1) Write out to reference the findings.

Cancer Registries

All 50 states of the United States have a cancer surveillance program which conducts routinely collection and compilation of identified demographic and clinical information of every identified malignant cancer diagnoses. The primary source for cancer trends over time and outcomes that can inform public health policies to act upon interventions to reduce cancer risks (McLaughlin, 2010).

There are two types of cancer registries listed as hospital based and population based. Hospital-based registries goal attainment is to improve patient care, educate patient and community of cancer risk, and provide clinical trial research. In reverse, population-based registries set their goals with cancer prevention, cancer rates and trends, control efforts evaluated and to report patterns of care and outcomes per regions (SEER, 2014). It's essential for the population-based system to monitor the state and local cancer patterns and trends but eleven years ago it would take two years to have completed and quality cases reported. The CDC has set standards for completeness, timeliness and quality as its value set at 95% completed and within six months date of diagnosis (Izquierdo, 2000).

The data from cancer registries (also called tumor registries) have been overlooked by researchers. Researchers would take the time to review medical records or other institutional databases to ascertain malignancies. As cancer data is being located on national level through the NCDB as broader use, researchers can utilize the information readily in a data structured view (Manasanch, 2011). Once a case is obtain during casefinding process a CTR must complete the abstracting within 6 months from initial date of diagnosis. During that time registries fail to complete an abstracted case due to patient not continuing care, moved out of state or treatment planned was not started. Even though the case might not be completed and the cancer treatment is noted in numerous medical records between medical specialists, the TR reflects the best and most accurate collection of cases by coding standards ICD9 and ICD-O for cancer research and care (Manasanch, 2011).

Quality of Cancer Data

The quality of cancer care requires a suitable measure of quality with available use of data to apply those measures. There are three interrelated goals to the quality of care: surveillance, quality improvement, and accountability. Surveillance involves the collection to identify problems, quality improvement collects data to construct improvement in care and for accountability the data is collected to compare those plans,

groups or providers (Malin, 2002). It is a national priority to evaluate and improve the quality of cancer.

The data that is store in cancer databases have key source information with stages and treatments that are mostly stored at hospital-based registry systems (Mallin, 2013). Most documentation of treatment rendered is given in outpatient settings, which some registries might not identify all treatments in progress notes in the hospital. There have been studies dating back to 1990s of registries not completing the documentation of chemotherapy, radiation therapies by 70% of cases (Mallin, 2013). It took time and logistically increases in funds to seek out data on treatment not provided at the hospital. CTR's or HIM analyst would have to send out yearly letters to patients and/or physician offices to gain access to the patient's treatment plan and follow up. As the process of HIM advocacy for electronic health systems the linkage between cancer database systems with administrative claims and pathology reports by ICD 9 codes and SNOMED codes.

Rapid Quality Reporting System

The states are supported in part with CDC's National Program of Cancer Registries; SEER program collects the more detailed information per regions of the country registries, as it is legislatively required to be reported. For those hospital-based registries under the accreditation by the CoC of the American College of Surgeons, programs must meet organizational and quality standards in data reported (Edge, 2013). In the reporting those cases registries submit them annually into National Cancer Data Base (NCDB).

NCDB provided tools to evaluate those patterns and survival outcomes for the registries then presented to public by summarizing each program resources and services (Edge, 2013). In 2005, the American College of Surgeons CoC had implemented the Cancer Program Practice Profile Reports (CP³R). CP³R was set to be in line with IOM objective for a nationwide reporting mechanism for those accredited program evidence-based consensus measuring the quality of care for breast and colorectal cancer (Stewart, 2011). By 2009, they were introduced into CoC program standards and few critiques were communicated that the reports were becoming to be out dated due to the ascertaining the status of treatment active.

By 2011, RQRS was added as an extension to CP³R reporting tool as to expedite the data entry, programs to report concurrently than retrospective, an up-to-date concordance rate to the state and other programs and the timing for treatment expectation notification tool (Stewart, 2011). This new quality of care tool mechanism gives an alert system to the cancer committee to ensure a timely and coordinated care in prompting treatment plan reviews and assure the process are in place to render the care (Stewart, 2011).

Chapter 3

Methodology

The search process to identify relevant articles conducted with an electronic library database. The search concluded with limited relevant article time frame of 2002 to 2014, with search engines PubMed/MEDLINE, CINAHL (Cumulative Index to Nursing and Allied Health) with full text, Scopus and Google Scholar. Searching within the databases and search engine the used subject headings and subheadings if available were combined with keywords. Search terms used included *cancer registry, cancer quality data, cancer database, electronic health systems and rapid quality review system, commission on cancer and cancer data.*

Selection Criteria

The article included if any one of the following:

1. Validity of cancer registry data
2. Utilization of rapid quality reporting system (RQRS)
3. Challenges viewed as a limitation to cancer data ascertained

The articles that were excluded in the search did not pertain to the topic but were reviewed before excluded. The process in selecting 14 articles (Table 2) out of 1,982 was determined by the title and abstract description in the searches. Only selected full text articles were reviewed for relevance and those that were not relevant to the topic and criteria were excluded.

Chapter 4

Results

Validity

The validity of cancer registry data continues to be studied among physicians and cancer data analyst on a daily routine. As the years pass by and the evolution of cancer registry, also called tumor registry, the ascertainment being conducted through electronic format the completed and valid key data must be reviewed for cancer research. Valid information on care provided is a prerequisite to accurately determining quality of care. Surveillance, Epidemiology, and End Results Program requires cancer programs to comply with a higher value ratio to show that the completeness of the cancer registry data for study but valid data is not as high. In 2005, National Quality Forum (NQF) initiated that there should be evidence-based quality measures in response to IOM report; with joint efforts with National Comprehensive Cancer Network (NCCN) and American Society of Clinical Oncology (ASCO), CoC established six measures for breast and colorectal cancer (Williams, 2012). The qualities measures that are needed to be met are scored on compliance are actively being conducted among cancer programs.

In 2002, Malin and colleagues study the validity of California Cancer Registry data as they wanted to compare the cancer registry data to medical record data of breast cancer incidences. They demonstrated in the study that hospital-based registry data had higher score rates compared to those ambulatory medical records documentation of breast cancer care. Cancer patients are predominantly diagnosed at a hospital-based cancer facility but also can be considered first site of diagnosis at ambulatory sites. The listing of ambulatory sites include specialist in breast, colon, urology, gynecologic, hematology and dermatology that can diagnosis a cancer incidence but follow up care is seen mostly at hospital facilities. The lost or miscommunicated treatment data between these facilities can show that hospital registry data is much higher than if the ambulatory site would.

Breast and colorectal cancer treatment plans were not identified up to 30% in the 1990s due to large scales and time consuming of reviewing medical records manually. In a comparison the review of payer claims were used as a benchmark for complete and valid cancer registry treatment information from Ohio residents insured by two large private payers. Its finding found that through the claims data that each breast or colorectal case was valid and completed per surgery but a portion of 13% to 15% data capturing of chemotherapy or radiation therapy was not captured. Kimberly Mallin and colleagues discovered in her research that between the years 2004 to 2006, registries were not capturing those radiation and systemic therapy data that was caused a

magnitude of missing data but no other study was looked into why this was not being conducted. The change happens within cancer registries understanding and gaining new knowledge to gain access to those ancillary department reports (Mallin, 2013).

The CoC and NCDB requires access to completed treatment data and by allowing this quality ratings have been studied with an increase in results of adjuvant and systemic therapies are being captured for valid and complete cancer registry data. The sensitivity of surgery data in research study between 1997 and 1998 improved from 92% to 98% in 2007 and 2009; radiation improved from 74% to 88%, chemotherapy 71% to 75% and hormonal therapy 49% to 69% (Williams, 2012). The growth has been somewhat improved by how cancer registries are reporting their statistics through a NCDB web-based auditing reporting tool called the Cancer Program Practices Profile Reports (CP³R) in 2005 and now has transformed over to another tool with more validity high ratings with the Rapid Quality Reporting System (RQRS) initiated in 2011.

In past few years two studies conducted audits demonstrating processes that could impact data collection and structural data to evaluate quality cancer care. Registry data requires adequate steps to be reliable and if not the data can be manipulated easily with reported treatment data misleading performance of care (Willis, 2011). Besides local registries conducting audits of cancer data, regional population-based registries proceed with auditing the data received by outpatient facilities. In the study by Adele Caldarella and colleagues the data was analyzed against quality measure indicators, particularly structural data, retrospectively of the Tuscany region. The study check for compliance against the indicators and validated the results through an *ad hoc* clinical survey that did indicated homogeneity of cancer quality care statistics (Caldarella, 2012). Auditing registry data is very feasible to identify any variable that could be of poor valid and reliable data. Data entry into cancer database software can alert validity flag checks to auditors to complete fields that are more important for research and standard compliance (Willis, 2011).

Challenges

Cancer registries are conducted as hospital-based or on population-based and with many cases being reported at local hospitals the data can be challenging to collect what is valid and correct. As treatments are moving to more outpatient settings to accommodate to those patients, required reporting is raising problem. Many metrics and standards are to be met by registries take different methodology in acquiring the needed information between institutions, care settings or providers. In a report by Goldberg and Conti (2014) the decline of physician owned private practices in oncology was 10% between 2010 and 2011 that in return increased the affiliations with larger provider oncology groups and hospitals. As physician transition over to bigger institutions for

better resources, this can affect their patients to continue their care if it's not in reach of their residency location.

In 2007, American College of Surgeons' (ACOS) Commission on Cancer (CoC) required steps for those accredited programs to submit all adjuvant treatment data for breast and colon cancer cases. The choice was targeted with these two top main cancer sites in requiring the data to be reported to National Cancer Database (NCDB). Gathering the data from outpatient settings develops a challenge with unreliable data. Nina Bickell et al (2013) suggested that academic medical centers only had 12% to 32% of radiation therapy, 8% to 29% chemotherapy and 0% to 3% hormonal treatment reported by local community and hospital-based oncologist. These therapies are critical to any quality improvement efforts as standards require cancer sites to be conducted with therapies in a specific time frame.

In this study by seeking the barriers to treatment reporting the three key barriers were: (1) burden of manual reporting, (2) inability to identify correct managing physician, and (3) poor communication (Bickell, 2013). Manual abstracting occurred in tumor registry with time consuming to locate records, analyze the case for valid treatment information. As the electronic health record was implementing the timing to locate a record was cut down but if a certain pathology report, consult and/or surgical note were not uploaded it took time for the registrar to send out request letters to receive the needed information. Bickell et al (2013) study found that it takes a registrar average 6 minutes per email, 5 minutes per fax, 3 minutes per letter and 8 minutes per phone call tracking treatment information.

Communication is a major key with any relationship between professional setting and personal setting. Tumor registrars are misunderstood in their role and goals among community-based physicians who are aware of an existing registry (Bickell, 2013). When a registrar sends out request forms to complete an abstract they require the minimum amount of information and with those request physicians are not sure if they should provide all or nothing. HIPPA has been judge many times among registries and physician offices in that they feel they are violating the patient's right to disseminate medical information. Nina Bickell qualitative assessment of these responses by physicians and administrative staff was seen as barrier to why the data needed was being depleted with those having no knowledge of the goals and role of any tumor registrar.

Information technology become obsolete when newer versions are introduced months, years and with many systems used in healthcare settings the communication among systems can be a barrier. Having the paper format of the treatment notes to be cumbersome it can never be easy to analyze what is needed to be pulled out to complete a valid cancer care reporting. IT introduced into cancer registry can help in

locating cancer cases with many ancillary department notes by pulling out those key codes and terms to be integrated to a cancer database software. As a result of this barrier, physician had learned to make due given the technologies they did or did not have in their practices (Bickell, 2013).

Last challenge in validating cancer registry data is the connection between physicians and hospitals. A patient sees their primary care physician on a yearly or monthly for care and if there seems to be a medical care they are not specialized to treat they refer to that specialist. In the transition the patient is to see the specialist for the proper diagnosis and begin a treatment plan or surveillance. The patient may choose to continue the communication between the physician on the care they are receiving and the community-based physician expressed that the hospital-based physician has the best interest in communicating the needed information for their knowledge (Bickell, 2013). It was explained by the interviewed participant, "When I refer a patient to one of the full-time oncologists, I almost never get reports back and patient disappears" (Bickell, 2013). This is seen many times and with patients even leaving with no notice to the institutions and physician office the data of their treatment can be missed if there is no new managing physician was noted in last follow up to contact for the updated treatment data.

Utilization of Rapid Quality Reporting System

There are three national cancer registry programs. Each state maintains a cancer registry with support from Center for Disease Control's National Program of Cancer Registries (Edge, 2013). Population-based registries report cancer incidences to the National Cancer Institute's Surveillance Epidemiology and End Results (SEER), with more detailed information of cancer sited per select regions of the country. By reporting to both the state and SEER it gives a study of cancer incidence and mortality but there is limited amount of treatment that has higher value to each research study. As for the data being collected for hospital-based cancer programs is accredited by the Commission on Cancer (CoC) of the American College of Surgeons. The data that is submitted annually is reported to the National Cancer Data Base (NCDB) to aggregate into a single registry for research and benchmarking among facilities.

The NCDB is used to evaluate cancer care retrospectively as there are over 1,500 accredited programs reporting in yearly and in 2005, the CoC developed a set of quality measures for breast and colorectal cancer to be measured on the quality of registry data (Edge, 2013). In the time frame for registries to measure the standards a reporting, Cancer Program Practice Profile Report (CP³R) to show the performance of the quality measures being completed and benchmark comparison among other hospitals. After four years of each registry conducting the reporting through the CP³R there was a delay in reporting data from 18 to 24 months after diagnosis in which Rapid

Quality Reporting System (RQRS) was introduced in 2009 to capture real-time clinical reporting. The Rapid Quality Reporting System is now being utilized among CoC accredited programs to concurrently collect and report data on patients, notification of treatment expectation in the hospital setting and exhibit up-to-date concordance rates compared to other hospitals at local, state and national levels (Raval et al, 2009).

In 2011, J. David Beatty and colleagues published a report in *The American Journal of Surgery* on the CP3R based on 6 guidelines for breast and colorectal cancer with cancer registry data. The method look at 593 breast cases, considered to be analytic, among 3 databases. In their results they showed that there was compliance per CP3R guidelines but a high discrepancy in the characteristic of the treatment and tumor that resulted in inaccurate and incomplete data (Beatty et al, 2011). The inaccuracy of the data and quality of the care was reported in their report that with more cancer care provided in outpatient setting the access to those ancillary documented reports makes the time frame of treatment per guidelines of 4 to 5 month into 8 to 12 month reporting (Beatty et al, 2011). J. Beatty (2011) reported, "Exploring linkage for synoptic pathology reports to be inserted directly into the cancer registry database, and evaluating the potential of electronic medical record as the primary source for data entry and minimize duplicate data collection."

In two states, Georgia and New Jersey, researchers concluded that in their analysis that RQRS has been shown to be a great method of identifying groups of patients not receiving proper care and such that a state-level cancer system could endorse rapid learning in adopting the real-time reporting system. Georgia researchers reported that state cancer plans are pervasive and hold the promise for cancer learning and quality improvement (Lipscomb and Gillespie, 2011).

In September 2009, Emory University was awarded a monetary amount by the Association of Schools of Public Health and partnership with Center for Disease Control to support "Using Cancer Registry and Other Data Sources to Track Measures of Care in Georgia" (Lipscomb and Gillespie, 2011). The project aimed to focus on breast and colorectal carcinoma incidences to be linked among multiple sources that can be deployed for quality of care assessment. The multiple source linkage was a success in gathering the data but time lag behind to be in accordance with quality measures of treatment time frame. Building a rapid learning system to gather cancer care concurrently would be beneficial with the available data across administration and clinical data.

Chapter 5

Discussion

The current studies in the articles reviewed processes in how cancer data is collected from multiple sources as the time gap between gatherings puts a decline in meeting quality standard measures. As the research question looking at how quality of cancer data can be improved, the studies were same before and after utilizing hospital-based quality measurable tool RQRS (see Table 2). There were other studies that showed similarity of challenges that interfered in getting the most valid and complete cancer treatment data (Table 2).

In order to have the best quality of cancer data, that is measureable to the standards, ascertainment must be met at its highest value among registries state, locally and nationally. Walker et al found in previous literature that the collection of adjuvant therapies were of low value but with newer process and tools implemented over the years the percent value has increased (Walker, 2013). Cancer programs have different policies and procedures in gathering the data and with IT software not being compatible between hospital-based and community-based practices it is not easy to have the data readily available to be analyzed. Bickell et al (2013) mention in their study that the software interfaces between the electronic medical record and tumor registry software can facilitate direct data transfer. As this time hospital cancer programs are working with oncology software in uploading cases linked to malignant carcinoma incidences but if that patient is not following somewhere else the data collection can be tough to find and time consuming to manually entering into the database.

Another problem that hinders the quality of cancer care reported is the active involvement among the medical staff and administration to have the knowledge of knowing the goals and roles of the cancer registry. Educating those physicians on the importance of reporting the needed information for hospital registries can improve the documentation and timing of treatment conducted in outpatient setting to the quality standards of care.

Future recommendations for researchers on the quality of cancer data collection need to re visit the challenges reexamine the participation of RQRS among hospital-based registry systems, and if there will be other processes to identify valid cancer data. Another recommendation in this study is to reassess the knowledge of physician and administrative staff understating of the roles and objective of a cancer registry. As the education gap was presented in the studies, having the knowledge can lead the registries process to increased validity ratio and completeness of cancer incidence reporting in the designated time frame per standards.

Chapter 6

Conclusion

This systematic review found an ample amount of scientific literature as it related to the quality of cancer care and cancer registry processes. All of the published reviews were consistent in how the process should proceed in ascertainment of treatment data, educating healthcare professionals on the goals and roles within the registry field, and how researchers view of rapid quality reporting system is valuable. In conclusion, tumor registries hospital-based participation with RQRS and making the connection among community –based practices will greater impact cancer research, marketing and evidence based guidelines for cancer care.

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